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## Sociocultural dimensions of tuberculosis: An overview of key concepts

### Abstract

Biomedical innovations are unlikely to provide effective and ethical tuberculosis (TB) control measures without complementary social science research. However, a strong interest in interdisciplinary work is often undermined by differences in language and concepts specific to each disciplinary approach. Accordingly, biological and social scientists need to learn how to communicate with each other. This article will outline key concepts relating to TB from medical anthropology and health sociology. Distilling these concepts in an introductory framework is intended to make this material accessible to researchers in laboratory, clinical and fieldwork settings, as well as to encourage more social scientists to engage with TB research among target groups critical for successful programmatic interventions. For pedagogical purposes, the relevant concepts are grouped into three categories: 1) structures and settings, which includes overarching themes such as syndemics, local biologies, medicalisation, structural violence and surveillance; 2) practices and processes, encompassing gender, stigma, taboo, and victim blaming; and 3) experience and enculturation, which includes illness narratives, biographical disruption and dynamic nominalism. By helping to navigate this literature, we hope to foster more cross-disciplinary conversations between qualitative and quantitative researchers. TB, a quintessential social disease, will be controlled more effectively using a multistranded research approach.

### Disciplines

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## **Sociocultural Dimensions of Tuberculosis: An overview of key concepts**

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### **Abstract:**

Biomedical innovations are unlikely to provide effective and ethical TB control measures without complementary social science research. However, a strong interest in interdisciplinary work is often undermined by differences in language and concepts specific to each disciplinary approach. Accordingly, biological and social scientists need to learn how to communicate with each other. This article will outline key concepts relating to tuberculosis from medical anthropology and health sociology. Distilling these concepts in an introductory framework is intended to make this material accessible for researchers in laboratory, clinical and fieldwork settings, as well as to encourage more social scientists to engage with tuberculosis research among target groups critical for successful programmatic interventions. For pedagogical purposes, the relevant concepts are grouped into three categories, (1) structures and settings, which includes overarching themes such as syndemics, local biologies, medicalisation, structural violence and surveillance, (2) practices and processes, encompassing gender, stigma, taboo, and victim blaming, and (3) experience and enculturation, which includes illness narratives, biographical disruption and dynamic nominalism. By helping to navigate this literature, we hope to foster more cross-disciplinary conversations between qualitative and quantitative researchers. Tuberculosis, a quintessential social disease, will be controlled more effectively using a multi-stranded research approach.

**Keywords:** Gender, Stigma, Surveillance, Syndemics, Social determinants

### **Abstract in French**

Les innovations du domaine biomédical ont peu de chances de fournir des mesures de lutte contre la tuberculose (TB) à la fois efficaces et éthiques sans recherché complémentaire en sciences sociales. Cependant, le grand intérêt vis-à-vis du travail interdisciplinaire est souvent entravé par des différences de langage et de concepts spécifiques à chaque approche disciplinaire. Les chercheurs en biologie et en sciences sociales doivent apprendre à communiquer entre eux. Cet article va exposer les concepts clés relatifs à la TB en anthropologie médicale et sciences sociales. Distiller ces concepts dans un cadre conceptuel introductif vise à rendre ce matériel accessible aux chercheurs dans les laboratoires, en clinique et sur le terrain, ainsi qu'à encourager davantage de chercheurs en sciences sociales à s'engager dans la recherche sur la TB au sein des groupes cibles cruciaux en termes de succès des interventions. Pour des raisons pédagogiques, les concepts pertinents sont groupés en trois catégories: 1) structures et contextes qui incluent des thèmes transversaux comme les syndémies, la biologie locale, la médicalisation, la violence structurelle et la surveillance; 2) les pratiques et processus incluant le genre, la stigmatisation, les tabous et la culpabilisation des victimes; et 3) l'expérience et l'inculturation qui incluent les récits de maladies, la rupture biographique et le nominalisme dynamique. En contribuant à s'y retrouver dans cette littérature, nous espérons favoriser davantage de conversations interdisciplinaires entre les chercheurs du domaine qualitatif et quantitatif. La TB, une maladie typiquement sociale, sera contrôlée plus efficacement grâce à une approche multicanaux.

### **Abstract in Spanish**

Es poco probable que las innovaciones biomédicas ofrezcan medidas eficaces y éticas para el control de la tuberculosis (TB) si no se acompañan de una investigación complementaria en ciencias sociales. Sin embargo, un interés acentuado en el trabajo interdisciplinario suele verse obstaculizado por diferencias en el lenguaje y los conceptos específicos de los enfoques de cada disciplina. En consecuencia, los investigadores de las ciencias biológicas y sociales deben aprender a comunicarse entre sí. En el presente artículo se destacan conceptos básicos en materia de TB, desde la perspectiva de la antropología médica y la sociología de la salud. Condensar estos conceptos en un marco introductorio tiene por objeto hacer que este material sea más accesible a los investigadores en los entornos de laboratorio y clínico y en el terreno, además de incitar cada vez más a los científicos de las ciencias sociales a participar en la investigación de la TB dirigida a los grupos clave, con el fin de mejorar la eficacia de las intervenciones programáticas. Con fines pedagógicos, los conceptos primordiales se agruparon en las siguientes tres categorías: 1) estructuras y entornos, que abarcan temas generales como las sindemias, las características biológicas locales, la medicalización, la violencia estructural y la vigilancia; 2) las prácticas y los procedimientos, que comprenden el género, los estigmas, los tabúes y la culpabilización de las víctimas; y 3) la experiencia y la asimilación cultural, que incluyen los discursos sobre las enfermedades, la ruptura biográfica y el nominalismo dinámico. Al ayudar a abordar esta literatura, se espera fomentar las conversaciones interdisciplinarias entre los profesionales de la investigación cualitativa y cuantitativa. La TB es una

enfermedad social por excelencia y su control será más eficaz cuando se aplique una estrategia polifacética de investigación.

## Introduction

Social histories of tuberculosis (TB) are numerous.<sup>e.g. 1-7</sup> Between them they cover the critical periods between the characterisation of the contagiousness of the disease in the 1860s, the identification of the causative agent, the development of the Bacillus Calmette–Guérin vaccination in the 1920s and the advent of chemotherapy in the 1940s. Robert Koch’s elucidation of the causative agent of TB in 1882 attuned public attention to the central role of the microbe in the aetiology and pathogenesis of the disease. The subsequent discovery of effective antimicrobial treatment for TB cemented the dominance of biomedicine over already declining rates of incidence in the developed world. In the developing world, however, the number of TB cases doubled in the thirty years between 1952-1982.<sup>8</sup> Increasing rates of incidence and morbidity amongst the world’s poorest and most disadvantaged populations did little to push TB onto the global health agenda until the 1980s New York TB epidemic stimulated renewed interest in developing better diagnostics, vaccines and antibiotics.

Against this background, economist and epidemiologist Hans T. Waaler called for a re-evaluation of basic principles, highlighting that increasing the detection and elimination of *Mycobacterium tuberculosis* has dramatic consequences and simultaneously draws attention away from “the socio-economic character of tuberculosis” and “the general living conditions in the generation of health.”<sup>9</sup> The social determinants of TB are well known,<sup>10</sup> but are not being adequately addressed.<sup>11,12</sup> Consequently, the emergence of drug-resistant TB can be considered an iatrogenic outcome of current biomedical and public health approaches to TB.<sup>13</sup> The oft-repeated words of René and Jean Dubos are particularly apt, that “the impact of social and economic factors on the individual be considered as much as the mechanisms by which tubercle bacilli cause damage to the human body”.<sup>14</sup> Studying the microorganism without studying the conditions under which it proliferates is like studying a seed but ignoring the soil.<sup>15</sup>

Despite the widespread availability of effective treatment, TB remains the second leading cause of death from infectious disease worldwide with 95% of cases and deaths estimated to occur in the developing world. In discussing the need to address deaths from preventable disease, this article describes a number of key concepts to help conceptualise the individual, interpersonal and structural issues related to TB (see figure 1). The three broad themes that this overview will address are:

- (1) Structures and settings: the conceptual frameworks that can be employed to situate TB not simply as an object of medical concern but as a site of contested practices.
- (2) Practices and processes: how the socially patterned attributes of stigma, gender, victim blaming, and taboos variably influence health-seeking behaviour and treatment adherence.
- (3) Experience and enculturation: the ways in which people make sense of their illness experience and the ways in which culture compels them to act.

**Figure 1:** Conceptualising socio-cultural considerations of tuberculosis care and prevention through three mutually impacting spheres operating at individual, interpersonal and structural levels.

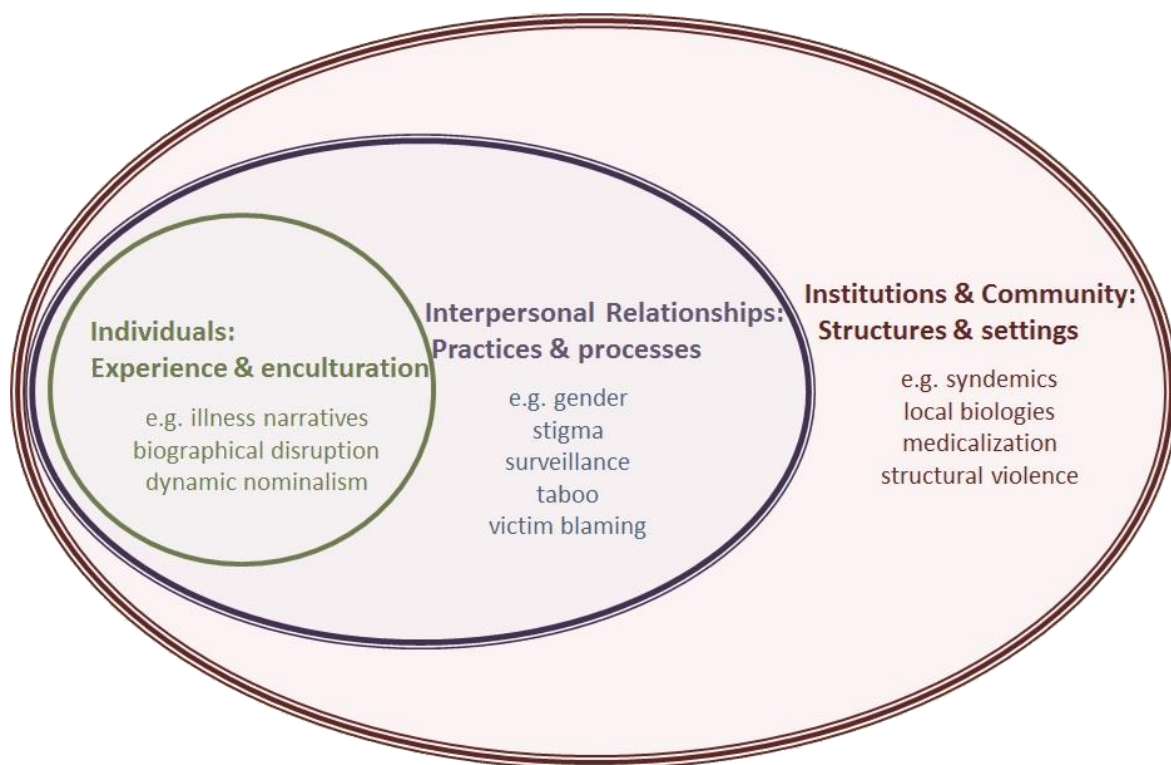


Figure 1 in French:

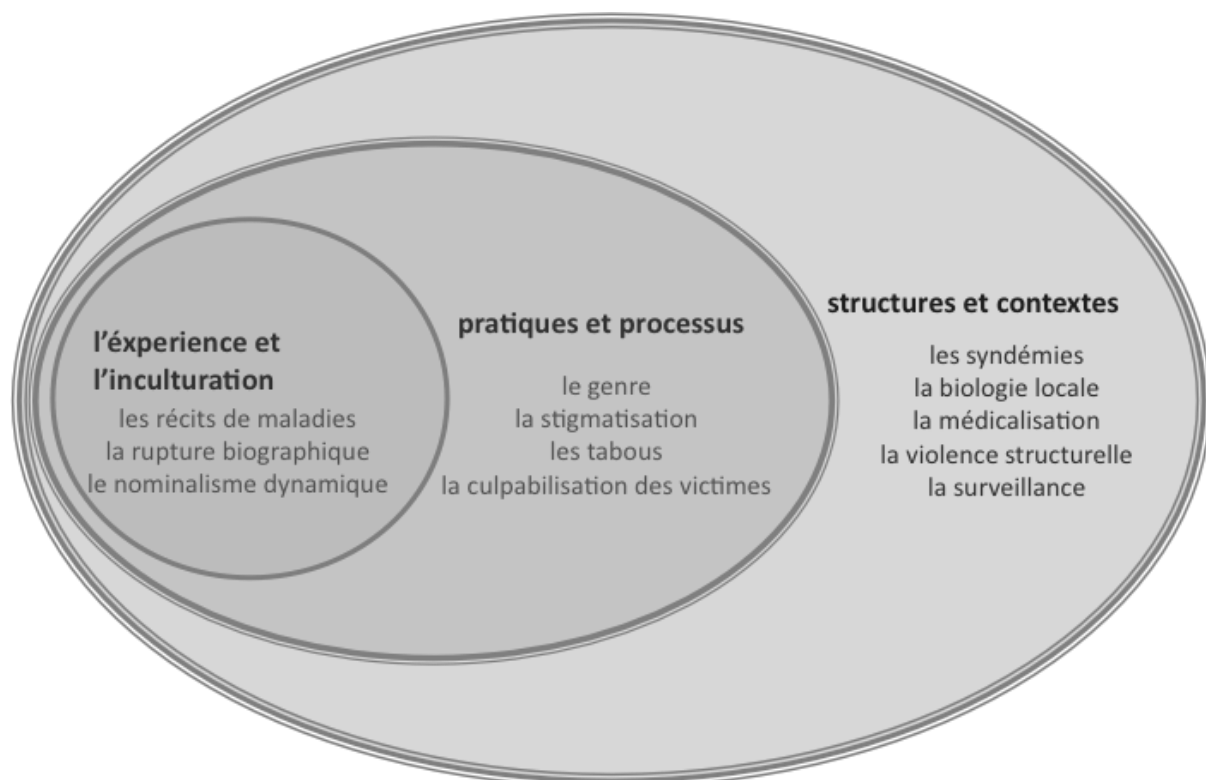
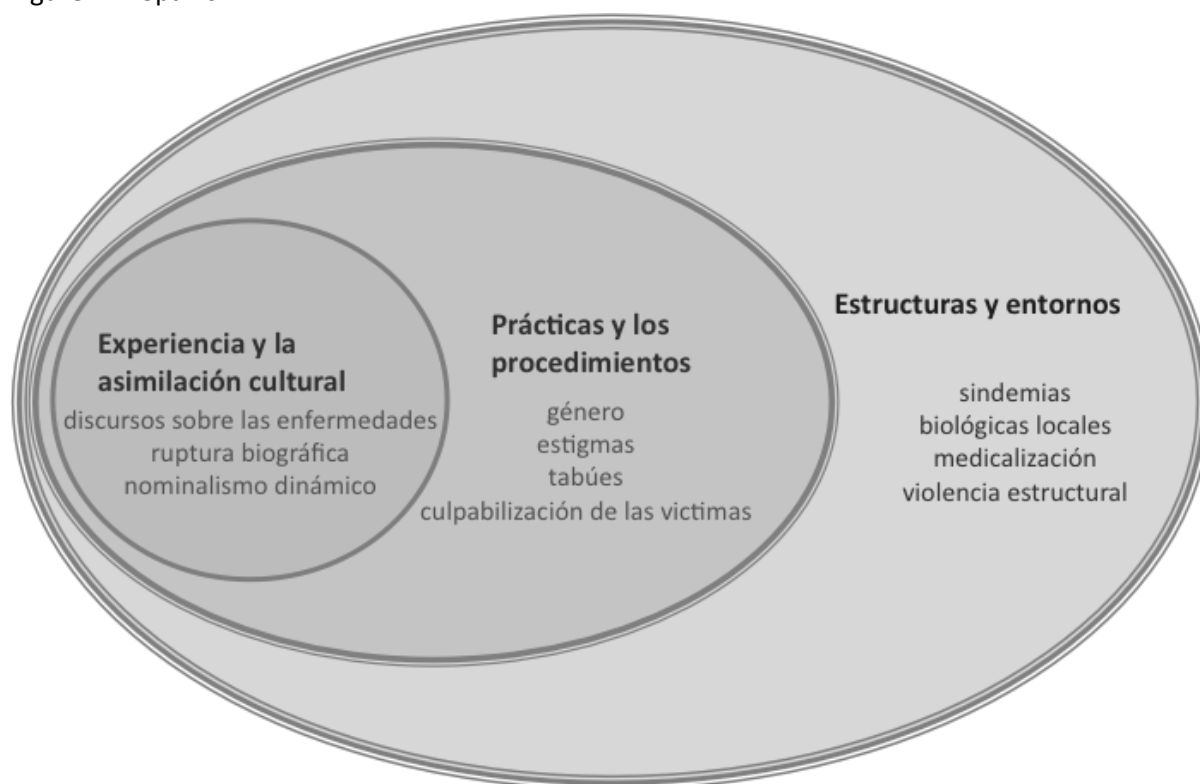


Figure 1 in Spanish:



Recognising that biomedical perspectives are one voice among many, this article is working towards a holistic picture of effective TB care and prevention. Substantial shortcomings in case-detection are not only due to the limitations in available diagnostic strategies and time-consuming laboratory tests.<sup>15,16</sup> Barriers to diagnosis and treatment also include social, economic, geographical, cultural, and political challenges. Conceptual tools from health sociology and medical anthropology offer useful ways to examine dimensions of public health that may escape the strictly biomedical paradigm. By recognising cultural experience as a central force shaping human interactions with the world, TB researchers and clinicians can develop a more nuanced consideration of how health, illness, and medical treatment are understood, interpreted, and confronted. Greater competency in understanding the social and cultural dimensions that impact TB patients presenting to doctors contributes to developing ways to reduce diagnostic delay, increase effective TB healthcare delivery, and stop the spread of TB disease.

## 1. Structures and Settings

Thirty years ago the epidemiologist Geoffrey Rose argued that medicine has a duty of care not only to individual patients but also to the communities and populations to which we all belong.<sup>18</sup> The central thesis that underpinned much of this work is that populations can be unhealthy, and that sick populations are more than the aggregate of sick individuals.<sup>19</sup> Against this background, infectious diseases such as TB, have, historically, most commonly been understood and approached in two ways: as matters of contamination and as matters of configuration.<sup>20</sup> From the perspective of contamination – disease is the transfer and progress of infectious pathogens between and within individuals. From the configuration perspective, the focus is not on the pathogen, but on the



contexts, structures and power relationships that promote disease expression. Even as contact exposure and host-pathogen interactions determine the disease state of individuals, these interactions take place in a social and material environment that can be configured in ways that enhance or inhibit pathogenicity. What this means is that social relationships and environments appear to exert direct influences on morbidity and mortality, including from TB. The way that society is organised exposes certain populations to a higher risk of TB infection, a greater chance of developing active TB disease, and a lower likelihood of accessing effective TB healthcare. Australian aboriginals, for example, are 11 times more likely to have TB than Australian-born non-Indigenous persons.<sup>21</sup>

The emergence of the biomedical perspective of disease, and the dominance of its discourse in the second half of the twentieth century, has had broader effects on society. Medicalisation is the process through which “medical jurisdiction, authority and practices” are extended into broader areas of people’s everyday lives.<sup>22</sup> Undesirable biological and social differences are pathologised – they become something that demands some form of medical intervention. Medicalisation orients individuals and societies to accept dominant conceptions of medicine and voluntarily participate in its practices. Whereas TB was previously primarily construed through the frame of configuration, the development of chemotherapeutic agents against TB accelerated the medicalisation of TB in public health discourse. Once primarily considered a social condition with a medical dimension, the incidence of TB disease was removed from its social context in expert discourse and public debate. Once the process of medicalisation begins, proposed solutions become increasingly technological, isolationist and consumerist in orientation, where existing structures and systems are seen as natural states, and, thereby, not amenable to reform.

Medicalisation is often co-constitutive of racialised understandings of disease – and this continues to be the case with TB in indigenous and migrant populations.<sup>23,24</sup> Genetic differences undoubtedly have a role in susceptibility to active TB infection, but ascription of the influence of race or ethnicity to susceptibility to TB remains, at best, controversial,<sup>25</sup> especially as other correlates such as socio-economic status can also explain why some populations have higher incidence of infection.<sup>26,27</sup> Yet social inequality in disease is only partially explained by the classic behavioural dimension of health risk exposure. Structural conditions can perpetrate violence against distinct populations by preventing them from meeting their most basic needs.<sup>28</sup> Structural violence is often an intrinsic, and, thereby, invisible feature of inequitable social arrangements where population differences in health and welfare are treated as the consequences of individual biology rather than the prevailing socio-structural conditions. Yet the susceptibility of indigenous populations to TB is not simply a product of their relative lack of immunity to the pathogens carried by European colonisers but is also due to the violence of colonisation: its dislocating influence on their daily lives, cultural practices and communal well-being.<sup>29</sup> Structural violence can occur in lockstep with medicalisation, but disproportionately impacts the most socially disadvantaged. Violence that is the result of the way society is structured can be explicit but is most often shrouded in shame, silence, or both. For many indigenous peoples, the erasure of the history of harms from colonisation, or their valorisation as ‘progress’ by dominant society, only compounds the effects of entrenched disadvantage for present generations.<sup>30-33</sup>

The influence of health inequalities, caused by poverty, structural violence and social disadvantage can result in a syndemic – where social conditions promote the clustering, synergistic interaction and additive negative health effects of two or more concurrent disease burdens in a population.<sup>34</sup> The

concept of a syndemic runs counter to the biomedical perspective that seeks to isolate pathological mechanism and treat the resulting diseases as instances of individual dysfunction. The spread of TB in populations and its course in individuals depends on co-factors such as HIV/AIDS and the conditions of poverty (malnutrition, poor hygiene, and high population density), all of which can promote public infection and activate latent TB in individuals. Of course, not all individuals exposed to the same syndemic risks end up with active disease. On this point, Margaret Lock's concept of local biologies is a useful counterpoint to syndemic thinking.<sup>35</sup> From the perspective of local biologies, individual and population level variations in biological responses to TB infection suggest that there is not a rigid separation between the biological and social aspects of the disease. These categories are not universal constants but the products of localised negotiations between social and biological processes and the material environment. At one level, syndemic thinking explains why disease incidence is higher amongst specific groups tied to specific conditions. At another level, the concept of local biologies, or perhaps more fittingly local mycobacteriologies, is an explanatory resource to understand the variation in disease expression within each of these clusters.

The medical anthropologist Erin Koch draws on the concept of local biologies to highlight the biosocial aspects of mycobacterial agency – especially as they are influenced by systems of care.<sup>36</sup> For example, diagnostic practices and TB management systems treat the bacillus as a fixed and stable entity whereas the boundary between “latent” and “active” infections in individuals is actually a dialectic between biology and sociocultural processes which makes this threshold labile and fuzzy. The TB cultured from a patient's sputum sample is only a snapshot (rendered in a laboratory) of a mutable relationship between two organisms (host and microbe) and their environments. Because TB can enter and lay dormant in human and animal bodies, activate and cause disease, and if challenged, develop antibiotic resistance, the current structures that focus on managing ‘active’ TB in populations only cause the microbe to evade elimination. Using the word threshold in a qualitative sense, Koch moves the focus away from TB as an object of intervention and towards TB as a zone of contested practices where arrangements of resources, medical expertise, forms of illness, and standards of biomedical response materialise through social, political and economic transformations.<sup>37</sup> TB is revealed or concealed according to the health-seeking behaviours of individuals, the level of mycobacteria in their sputum, and the sensitivity and specificity of the diagnostic tools available. The identification of latent TB infection (LTBI) as necessitating preventative treatment in low-burden settings but not in high-burden settings is a pragmatic example of how diagnostic labels emerge in concert with available resources, economic factors and disease burden. The controversy about proposals to conduct LTBI screening prior to immigration to low-burden countries such as Australia draws attention to how diagnosis can be used politically in localised negotiations to become literally a boundary to entry.<sup>38</sup>

The border control practices of screening migrants for TB is one example of TB surveillance.<sup>23,24,39-41</sup> Other scales of surveillance include the contact investigation of active TB cases,<sup>42,43</sup> the molecular genotyping of TB to determine transmission networks,<sup>44-46</sup> as well as the monitoring of TB patients through Directly Observed Treatment (DOT), the standardised model of TB treatment advocated by the WHO. DOT can interact synergistically or antagonistically with social stigma and socially-acceptable gender practices by structurally reinforcing the notion that individuals with TB are untrustworthy or not capable.<sup>33,47</sup> Direct observation of TB patients comes out of a colonial model of medical provision that was initiated in Madras and Hong Kong in the 1950s.<sup>48</sup> However, this model can be counterproductive in some settings,<sup>49</sup> and partially effective in others.<sup>50</sup> Surveillance has

historical significance in many settings and particularly among marginalised populations. With regards to TB among immigrant populations, anthropological research has moved the focus of attention away from a narrow concern with the country of birth, and towards a concern with the conditions of settlement and the circumstances that promote the reactivation of latent TB infection in migrant communities, including poverty and discrimination, life history, and the experiences of migrants in transit and after arrival.<sup>51</sup> While monitoring TB at the border is important, anthropologists have advocated that support for migrants, their social participation, access to health care and rights to freedom from discrimination are also key to reducing reactivation of TB.<sup>52</sup> Surveillance may be a hallmark of global health efforts. However, given its interaction with stigma, gender and marginalisation, surveillance is, to borrow the words of medical anthropologist Mark Nichter, “a practice that needs to be conducted reflexively” such that its goals and central assumptions should be iteratively reassessed on an ongoing basis.<sup>53</sup>

The concepts of syndemic, local biologies, and threshold are useful because they seek to add contextual dimensions to the biomedical perspective – they draw attention to the social, political and historical context of disease incidence and the microbial agency that comprises much of the dynamic nature of TB infections. As variations in the success of surveillance systems such as DOT illustrates, treatments for TB in individuals and populations that do not simultaneously seek to address its dynamic and syndemic features – and bend with local biosocial conditions – are less likely to be effective.<sup>11,12</sup> Informed by syndemic thinking and an appreciation that individual outcomes depend on the local interaction of biological and social processes, from a settings perspective the current emphasis on DOT and developing pharmaceutical solutions amounts to the medicalization of poverty.<sup>54</sup>

## **2. Practices and Processes:**

The ways people react to TB are shaped by broad social practices and cultural processes. Despite its curability, TB can lead to social vulnerability. The coughing of people with active TB disease can result in the production of bloody sputum, a bodily waste associated with physical contamination and unacceptable contagion. People who exhibit the unpleasant bodily fluids of TB, or other undesirable physical traits associated with the risks and dangers of TB, may withdraw or be withdrawn from social contact in order to contain their discrediting symptoms within the private domain. Compounded by local beliefs as well as associations to poverty and co-morbidities such as HIV/AIDS, the stigmatisation of TB is not easily unpacked.

Taken from the work of symbolic interactionist, Erving Goffman (1922-1982), stigma is a useful concept to analyse some of the issues facing people with tuberculosis.<sup>55</sup> Stigma is the discrediting or devaluing of an individual or group who exhibits persistent attributes, traits, or behaviours that are viewed as inferior, culturally unacceptable, or worthy of punitive response.<sup>56,57</sup> Effects of stigma include reduced social status, discrimination and exclusion. Denying specific individuals and groups the opportunity to fully participate in and attain the rewards from a society adversely impacts upon healthy living, health-seeking behaviour, and treatment outcomes.

Victim blaming is a common form of stigma surrounding TB where patients, particularly those who have developed drug resistant disease, are seen as responsible for their own illness.<sup>58</sup> A derogatory

focus on the patient impacts upon the agency of an already vulnerable individual and draws attention away from creating an enabling environment for successful treatment outcomes. Often closely associated with structural violence, victim blaming detracts from bringing about necessary social change for better public health by misdirecting attention away from assembling more qualified human resources, improving health infrastructure, and building stronger health systems that coordinate effectively with the private sector. Rather than locating illness in the context of broader social, historical and political structures, stigma places shame, blame and embarrassment on the individual.

Understanding stigma through social relations assists in examining various social taboos that people with TB have to endure. Studies conducted in Zambia, South Africa, and Kenya show that family members maintain various social taboos such as not sharing food, kitchen utensils, and beds with TB patients even after they have commenced treatment.<sup>59-61</sup> As a theoretical counterpart to stigma, the study of taboos provides an insight into the social practices that accompany stigmatising medical labels such as TB. Taboos shape social interactions by structuring vulnerable relations and help to maintain social order by threatening specific dangers should they be broken.<sup>62</sup>

A cultural minefield of taboos can be opened up by the conspicuous symptoms of active TB disease, which in some contexts may be strongly associated with physical contamination and unacceptable contagion. But dominant taboos can weaken over time,<sup>63</sup> and stigmas can be challenged.<sup>64</sup> Learning to understand the social basis of stigma and the social practice of taboos in any particular setting can help TB clinicians and researchers to navigate and contest the isolating social practices that impact negatively upon health-seeking behaviour and treatment compliance for a disease that is actually treatable and unnecessarily stigmatised.

TB-related stigmas can greatly exacerbate existing gender inequalities.<sup>65-67</sup> TB control programs substantially neglect the gendered dimension of TB around the world.<sup>68</sup> “Gender” encompasses the variety of behaviours, expectations, and roles that exist within a social, economic, and cultural context. The social construction of gender can variably influence lifestyle factors, health-seeking behaviour, and ultimately life chances. A consideration of the role of gender is important when addressing TB screening, diagnosis, and treatment adherence. The responsibilities associated to specific gender roles prescribed by a society might place some individuals more at risk of contracting and developing TB, affect compliance to a lengthy treatment program, or restrict the willingness to participate in diagnostic procedures such as producing sputum.

Worldwide, TB cases among men exceed those found in women by a ratio of 2:1. However, this global data conceals the local diversity of sex differences in TB rates. According to the notification rates reported by country in the 2013 WHO Global Tuberculosis Report, male to female ratios of TB can vary from 1:2 in Afghanistan, to 1:1 in Pakistan, to around 2:1 in India, and at its most extreme 3:1 in Vietnam.<sup>69</sup> Evidently, context-specific gender dynamics are at play. Documenting the sex distribution of notified TB cases in any one setting does not fully capture the relevance of social and cultural dimensions of gender for TB care and prevention.<sup>70</sup> The considerable divergence in TB ratios is likely a result of local arrangements of biological, social and cultural variables including access to care, structural factors, ethnicity, the particular strain of TB, and co-epidemics such as HIV/AIDS.<sup>71</sup> Depending on context, culturally embodied gender norms may put one gender at a higher social risk of being infected, expose them to more deleterious social outcomes as a consequence of active

disease, and limit their full engagement in healthcare activities. For example, studies in India have found that married women and single men experience lower levels of family support to initiate and complete treatment.<sup>72,73</sup> With fears of harassment by in-laws, rejection by their husband, and dismissal from work, married Indian women found the strain of secrecy and the pressures of housework to be significant obstacles to treatment adherence. Social studies of TB and gender are imperative and should focus on asking how a diagnosis of TB challenges social constructions of gender in diverse cultural contexts. Men and women follow different pathways to seek diagnosis and treatment and in some settings these labyrinthine pathways can lead to a huge shortfall in the number of people who present to TB clinics and complete treatment. Capturing how gender is constructed, performed, and challenged in the social spaces where TB diagnoses are revealed and concealed can lead to transformative healthcare practices that promote the social inclusion of all TB patients.

### **3. Experience and enculturation:**

TB is not just a clinical diagnosis but also a social experience. As the previous section makes clear, our social interactions are culturally patterned. Not only do these patterns shape how people with TB are perceived, but also how they perceive themselves, and how they experience the world. Prior to the availability of an effective treatment, TB was thought of as a chronic disease.<sup>74</sup> Considering that effective TB treatment still fails to reach large populations in mainly developing nations, the illness can still be thought of as chronic in many parts of the world. In such places, the onset of TB can be conceptualised as a disruption to a person's biography – their conception of themselves and their future. Disruptions in biography alter assumptions about the healthy body, social relationships, and the ability to mobilise material resources such that the:

erstwhile taken-for-granted world of everyday life becomes a burden, of conscious and deliberate action.<sup>75</sup>

Life stage and social situation mediate the effect of a diagnosis of a chronic illness.<sup>76</sup> In complement to the concept of biographical disruption, a constructive analytical device to interrogate the patient experience is their illness narrative.<sup>77-80</sup> Illness narratives are personal accounts that give meaning to a condition, and are part of the process of ongoing self-construction. The illness narratives of TB patients contrast markedly to the narratives presented by people afflicted by other diseases.<sup>81</sup> Given that the initial stages of TB disease can be indistinct from other diseases, the illness narratives of TB patients can provide insight into diagnostic delay, barriers to treatment, and the obstacles in achieving a successful treatment outcome. Chronic illness, however, is not only a cause of biographical disruption, but can also be a consequence.<sup>76</sup> For example, disruption caused by famine, co-morbidity, or other factors might trigger the onset of TB illness. In both scenarios, attention to illness narratives and biographical disruption champions the articulation of voices and concerns that might not otherwise be heard. A consideration of biographical disruption and illness narratives helps take into account the context within which TB occurs and the meanings through which patients understand their condition.

As well as comprising points of biographical disruption, the diagnostic labels applied to people with TB have consequences for their social identity and influence the forms of experience that are

possible for them. The philosopher of science Ian Hacking called this “dynamic nominalism”, the idea “that numerous kinds of human being and human acts come into being hand in hand with our invention of the categories labeling them”.<sup>82</sup> Dynamic nominalism is a useful way to think about the lay and biomedical classifications of TB patients, and a particularly poignant way of thinking about people who are labelled as noncompliant because they fail to adhere to treatment or those who develop multidrug resistant TB (MDR TB). As a “looping effect”,<sup>83</sup> classifications impact upon the way people act, and their subsequent understanding, experience and behaviours evolve iteratively so that classifications and descriptions in turn are constantly being revised. In this conceptual framework, MDR TB, within certain contexts, can be seen as the flux of a looping effect between TB patients and their treatment regimen. Diagnostic labels become embedded social norms that mediate individual experience, and, thereby, have biological consequences.

Another example of dynamic nominalism is the “at-risk” classification of a diagnosis of latent TB infection (LTBI). People labelled as having LTBI are diagnosed as being at-risk of an illness without showing any signs or symptoms of disease. This classification exposes a vulnerability that can lead a person to adopt measures to keep a latent illness in check either through treatment or frequent surveillance.<sup>84</sup> The vulnerability is not only biological, but also social, economic and political. A dominant biomedical discourse encourages pre-symptomatic people labelled at-risk of developing active TB disease to understand their bodies as needing to be sanitised. In the struggle against vulnerability, new vulnerabilities, ambiguities and uncertainties are created.<sup>85,86</sup> Is the LTBI a drug-sensitive or drug-resistant strain of *Mycobacterium tuberculosis*? What are the short- and long-term side effects of chemotherapy? What happens if an individual is potentially re-infected after LTBI treatment? While the biomedical model asks which objective risks are acceptable, an anthropological approach asks which vulnerability transformations are desirable.<sup>86</sup> LTBI exists within a ‘liminal’ space, at the junction between health and illness. Conceptualised as having a liminal body,<sup>87</sup> people with LTBI can be left trying to consider factors that may be unknowable and unable to be completely taken into account. When ‘at-risk’ becomes a biomedical classification, the presence of active disease is not always a prerequisite for defining who is a patient. Decision-making processes about diagnostic categories and what constitutes an appropriate response to LTBI involves more than just a consideration of diagnostic biomarkers of TB, but also a consideration of the ways that medical labels are socially, economically and politically contested.

The strategies and forms of coping that people exhibit in the face of TB and LTBI are influenced by cultural imperatives. A technological imperative, for example, can compel TB patients and healthcare practitioners to use available technology even when it is excessive, futile, or detrimental.<sup>88</sup> Using technology because it exists rather than because it is clinically necessary can lead to problems. In India, for example, suboptimal tests are administered to diagnose TB because they are available not because they are effective and recommended by the WHO.<sup>89</sup> The implementation of technology is not simply driven by its efficacy but mediated by social, economic, and political processes. Examining these dimensions of health care technology is important because the adoption and application of technology is an intensely political and profitable activity. When technology is used regardless of whether it is useful, superfluous, or injurious, the technological imperative needs to be assessed to ensure ethical, accurate and economically sound decisions. Other cultural imperatives include an imperative to be isolated, to travel long distances for treatment, or even an imperative to undergo surgery. When, where, and how bodily conditions are diagnosed and treated are all questions open to cultural influence and are all questions that should be regularly submitted to critical inquiry. A

self-reflexive approach to biomedical practice can help us become more aware of the relationship between social encounters and individual experience.

### **Concluding remarks**

This article has attempted to bring key concepts from the social model to bear on the problem of TB in order to create more balanced discussions and a space for researchers to share a common vocabulary. Our aim is to assist researchers and practitioners in finding and interpreting scholarship that is relevant to their interests and concerns and encourage more research that draws upon, interrogates, and advances the integration of the sociocultural dimensions of TB in to policy and practice. TB transmission and the medical practices that emerge in response to TB disease are social enterprises. The ultimate success of any intervention depends upon social factors because sociocultural determinants shape people's lives, exposure to disease, illness experience, response to risks, ability to take action, and capacity to employ preventative measures. The social model reveals the complexity of TB ecology beyond a simple chain of causation. The impacts of TB extend beyond the individual through their social networks and to broader society. The burdens imposed are more than the aggregated impacts of individual cases. Applying social science insights to contemporary practices in TB clinics and research laboratories allows for biomedical developments to be employed in ways that are most likely to be effective in local contexts. Beyond quantifiable outcomes, too, incorporating these insights into refining TB services and strategies will encourage the establishment of programs that “make sense” to both practitioners and affected communities. Only through understanding the influences and priorities underlying our engagement with TB can we continue to move beyond simple disease control and towards the elimination of every aspect of the pain and suffering caused by this disease in our world today.

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